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SHORT COMMUNICATION

Granting wishes: parents' perception of a wish fulfilment for a child with a life-threatening illness

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Research has consistently shown that negative life events disadvantage children in terms of health and quality of life (1). However, the emerging field of positive psychology (2) has led to research into the influence of positive emotionality on aspects of health (3). For instance, a recent study in adults specifically focusing on positive life events showed that these life events predicted cortisol levels (4). In addition, in the context of end-of-life care in adults, positive life events have been shown to have a favourable impact on well-being (5). In children, a positive life event, for instance, has been shown to counteract the risk of exacerbating asthma (6). The studies point to a growing interest in the influence of positive rather than negative life events.

Nowadays positive life experiences are often offered to children with a life-threatening condition. Children are offered to participate in special events by charitable organizations, in order to create an unforgettable positive experience for the child and their family. One such organization is the Make-a-Wish Foundation, the Netherlands (M-a-W NL), which is part of The Make-A-Wish Foundation®, which grants children's wishes (such as swimming with dolphins or experiencing a day as a fireman). Many of such organizations organize events within the medical domain under the hypothesis that these events improve the lives of the recipients, that is, the participating patients and their families. Research on such activities (7,8) and the impact on patients and families have been particularly scarce, and it is therefore not clear to what extent they succeed in delivering this aim. Conversely, ethical points about the acceptability of these well-meant practices can be raised. While the event is likely to bring joy and energy, it is equally likely that the event may lead to exhaustion and therefore diminished well-being after the event. Being offered a wish might even be experienced as a 'death sentence' as the wish is only offered to children who have a life-threatening illness.

Anecdotal evidence from reports from children whose wish was granted suggests that children and parents experience improvements in well-being and coping. There are also suggestions that for parents, once a child has died, the memories of the event may aid the bereavement process. However, negative outcomes are rarely discussed.

This study, therefore, set out to retrospectively investigate the experience of children and parents during and after a wish is granted. Specifically, we were interested in finding out (i) what the general impression of parents was of such an event, (ii) whether it improved well-being and coping after the event and (iii) the influence of the event on bereavement for parents.

The study was a cross-sectional retrospective investigation of parents of children who had a wish granted by the Make-a-Wish Foundation, the Netherlands. In the first instance, semistructured interviews were held with 17 sets of parents, which were independently analysed by two researchers to inform the development of a questionnaire. The written survey was developed drawing on the themes that emerged from this qualitative investigation of parents' experiences of the wish fulfilment. Two groups of parents were invited to take part in the survey part of the study: (i) parents of children who were alive at the time of the study and (ii) parents of children who had died before the study assessment. Parents were randomly selected from the

Foundation's database of children who had their wish fulfilled between 2004 and 2007 ensuring a proportion of participants were invited from each year (approximately 50%), and data were collected in 2009. In the first instance, all parents were contacted by telephone by volunteers from the Foundation and asked whether they would like to receive additional written information about the study from the researchers at the Erasmus MC. A total of 497 parents were contacted, and 398 (80%) indicated wanting more information; 74.1% of those (n = 295) were parents whose child was alive at the time of the study; 25.9% (n = 103) were parents whose child had died before the start of the study. The study was approved by the Erasmus MC Ethics Committee (nr: MEC.2009-010), in accordance with the Helsinki Declaration of 1975, as revised in 1983.

The postal questionnaire contained questions on demographic information about the child and parents. In addition, the questionnaire consisted of statements about experiences during and after the wish, to which parents could respond to on a five-point scale ranging from disagree (1) to agree (5). Two versions of the questionnaire were created; one for parents who had a child with a life-threatening illness and one for parents whose child had died before the study assessment. The latter was similar but included questions on the influence of the event on bereavement. Nine statements were presented pertaining to experiences during the event and eight statements on experiences after the event. Statements focused on their overall experience of the wish, changes in well-being (such as physical and psychological functioning, and quality of life) and coping during and after the event, and possible negative feelings about the wish (statements presented in Table S1).

Analyses were run using SPSS, version 17. Demographics were reported for all patients and parents. Results in the text are presented as the percentage of parents who responded 'agree' (response option 5) to the presented statements (the table presents percentages of all response categories).

Of the 389 parents who requested more information and a questionnaire, 235 parents completed the questionnaire, resulting in a response rate of 59%. The majority of questionnaires were completed by parents whose child was still alive at the time of study (n = 174 (74%) versus n = 61 (26%). Questionnaires were mostly completed by mothers (79.6%). Mean age of the parents was 44.5 years (SD = 6.2, range 28–62 years). Of the children who were alive, 48 (27.6%) suffered from oncological illness, 39 (22.4%) muscular disease, 16 (9.2%) metabolic disease, 18 (10.3%) lung disease, 5 (2.9) heart disease, 2 (1.1%) infectious disease and 44 (25.3%) from a combination or a different disease (n = 2 missing information). Of the children who had died before the time of the study, 44 (72.1%) suffered from oncological disease, 2 (3.3%) from muscular disease and 10 (16.4%) from a combination or a different disease (n = 5 missing information). Mean age of the children who were alive at the time of assessment was 11.44 years (SD 4.57) and 9.58 years (SD 5.00) for children who had died before the study. In total, parents of 68 girls (39.1%) and 106 boys (60.9%) participated in the study.

Almost all parents (92%) indicated that the experience was a positive one (Table S1). Asked whether the wish could be classed as a major life event, such as the birth of a child or a wedding, 33% agreed with this statement. The majority of parents (47%) agreed with the statement that their child momentarily did not feel ill during the event. More than half of parents (35%) agreed that the wish allowed them to be distracted from the illness and their children did not seem ill.

Parents often felt sad as well as happy, which is confirmed by the finding that 47% of parents agreed with the statement that they felt 'conflicted'; on the one hand, they were happy that their child's wish was being fulfilled; on the other hand, they were sad that their child was ill enough to be eligible. Moreover, 30% of parents agreed that the wish was experienced as a repeated confirmation that their child had a life-threatening illness.

The event is an important memory for 84% of parents. In terms of changes over time, 10% of parents indicated that they agreed with the statement that their child's quality of life had increased after the event. The specific statements on improvements in physical (5%) and mental functioning (16%) showed agreement for only a small number of children. Improvements in the child's energy levels were reported by 12% of parents while a decrease in energy was reported by 8% parents. Just 2% of parents agreed with the statement that coping improved after the wish fulfilment.

For those parents whose child had died before the start of the study, 21% agreed with the statement that the wish fulfilment helped with bereavement.

This study was the first to explore, in a large sample, the influence of having a wish granted by a charitable organization on the well-being of children and parents. The results show that on the whole, the experience is a positive one with children experiencing more energy and parents being distracted from their child's illness. Positive effects of the wish are particularly present *during* the event. Enduring effects over time, in terms of improvement in quality of life, levels of physical and psychological functioning and coping were reported by a minority of parents. In addition, for approximately half of parents the experience triggered bittersweet emotions; feeling happy as it is a hugely enjoyable event, while at the same time, feeling sad because the child's life-threatening illness means that he/she is eligible for a wish.

The strength of the study lies in the large sample of parents completing the questionnaire, with a good response rate for a postal questionnaire study. The limitations lie in the possible bias of the sample, with parents who had an overwhelmingly positive experience possibly being more likely to reply. In addition, parents of children who had died were less likely to participate than parents whose child was alive. The retrospective nature of the study limits our interpretation of the effect of the wish and future studies

should aim to investigate these factors prospectively and include the children when possible as well, using standardized measures of quality of life and adjustment.

In conclusion, the wish is a positive experience that is thoroughly enjoyed by the patients and parents. Conversely, the event is accompanied by negative feelings, as the life-threatening nature of the child's illness is continuously confirmed. Overall, the positive impact seems to prevail to a large degree, indicating that, from an ethical point of view, these activities should not be discouraged. Lasting psychological effects, apart from having an important positive memory, are only observed by a minority, which emphasizes that such expectations in parents should not be reinforced.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Table S1 Percentages of responses to statement about the wish, for each response option (disagree to agree).

